DOCUMENT RESUME

ED 415 458 CG 028 229

AUTHOR	Yazak, Daniel L.
TITLE	Chronic Illness and School to Work Transition.
PUB DATE	1998-00-00
NOTE	15p.
PUB TYPE	Reports - Research (143)
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	*Adjustment (To Environment); Career Choice; *Career Development; *Chronic Illness; *Decision Making Skills; *Education Work Relationship; Guidance; Secondary Education; Special Needs Students
IDENTIFIERS	*School to Work Transition

ABSTRACT

Chronic illness life management skills and school-to-work transition are separate but interrelated issues which are necessary for students, families, and caregivers to understand. The interconnection of these concerns is examined . Career choice is a process that involves the student, family, and appropriate professionals. Definitions of work life, adulthood, chronic illness, and an explication of the uniqueness of school-to-work transitions are offered. An evolution of transition programs is presented, as is an overview of career development. The latter is defined as a long-term endeavor in which an individual matches interests and abilities with opportunity and availability. The effects of chronic illness on career development, such as limited exposure to career opportunities and preconceived notions of what those with chronic illness can accomplish, are also examined. Some of the probable outcomes for chronically ill students are discussed. Much of the paper is devoted to the evolution of transition, with a focus on individual and family decision making, school services, and postsecondary opportunities. Students with chronic illness often feel isolated, different, and not worth attention by others. These students need feedback to help from future behavior and decision making involving social skills. A list of career specific assessment instruments and systems is included. (Contains 24 references.) (RJM)

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Daniel L. Yazak

Montana State University-Billings

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Abstract

Students with chronic illnesses present with life management issues which complicate an already complex process of career transition from high school. Career choice is introduced as a process that involves the student, family, and appropriate professional. The student's role in decision making is emphasized. Similarities with historical transition for at risk groups are presented; similarities with normal populations are considered. An inventory of assessment systems and instruments is presented. Suggestions for further research into the constructs of normalization and validity are made.

Chronic Illness and School to Work Transition

Introduction

Chronic illness life management and school to work transition are separate but interrelated issues which are necessary for students, families, and caregivers to understand. The process of moving from school to work while dealing with chronic life management issues should be understood in contexts that are different from those contained in transitions without chronic illness issues (Hanley-Maxwell & Collet-Klingenberg, 1995; Syzmanski, Hanley-Maxwell, & Asselin, 1992). While similarities exist, transitions are enhanced when individual strengths and weakness are assessed and appropriate plans for life management are made.

Issues of life management and school to work transition may present as interrelated, clarification of terms and constructs should lessen confusion and focus services. Students, families, and caregivers should mutually agree on the extent of involvement in the services provided; however, as much as possible, the student should begin to take an ever increasingly important role in the transition process. Much like the ego states and transactional analysis suggested by Berne, the development from child to adult should be recognized and facilitated (Berne, 1994).

Terms

Work life and adulthood are often viewed as synonymous. While the vocation of children and adolescents can be viewed as education, vocation for adults is often defined in terms of a career choice. As the vocation of education is not a choice for the child and early adolescent, a career choice is important for the latter adolescent and early adult years. The importance of the decision, however, is confused given the life management consistent with physical, emotional, spiritual, and

cognitive maturation (Pallas, 1993). Confusion can be compounded given issues of chronic illness.

Definitions of school to work transitions vary. One area of service provision that has developed concerning transition issues exists through the Transition Initiative of the Office of Special Education and Rehabilitation Services (OSERS). A definition of transition used by OSERS is "an outcome-oriented process encompassing a broad array of services and experiences that lead to employment" (Will, 1984, p.2).

The field of rehabilitation counseling further refines the concept of transition following the leads of national initiatives such as America 2000 (U.S. Department of Education, 1991), and the 1992 amendments to the Rehabilitation Act (Public Law 102-569). These initiatives have directed interest and sometimes mandated services to include choice and self-determination. When providing transition services to students with chronic illness, similar initiatives and service emphases should continue.

While terms of art such as transitional employment and supported employment from the field of rehabilitation may be an inexact fit for issues emanating from chronic illness, similarities do exist. For instance, examining the need of ongoing support to obtain, maintain, and advance in employment situations may be appropriate for individuals with chronic illnesses. Additionally, higher education; individualized living arrangements; and job skills, knowledge, and aptitudes might be included for examination and application as dictated by the individual.

It appears as though much can be learned from the field of rehabilitation. Extant methods and techniques for providing successful transition services abound. However, a more individualized transition process is indicated for students with chronic illness. Time limited and person intensive services more likely will characterize transition services to the chronically ill.

Transition

School to work transition is a part of the developmental processes that define the uniqueness of the human condition. This unique set of conditions can be viewed through a number of diverse theories and constructs. In order to best serve the transition process for students with chronic illnesses, the concepts of history, career, and school-work interface might make up a foundation for understanding the current state of transition.

History

As the twentieth century draws to a close, an evolution of transition programs can be determined (Parker & Syzmanski, 1998). For instance, at the beginning of the century higher education was seen as a choice which was made in exclusion of other career choices. By the end of the century higher education is seen more and more often and sine quo non for many career choices. It appears as though some high school education was foundational for career choices in the early 1900s; by the late 1990s a college degree is foundational. Legislators, educators, and tax payers have all participated in the discussion of weighing the merits of this evolution. What ever the outcomes of the debate, transition to career choice and employment is now more complicated than it was in the past.

Assistance in the transition process has often been accomplished through education and vocational rehabilitation agencies. Education agencies provide services to those individual enrolled in classes, while at the same time providing additional special education services to those meeting certain eligibility requirements. For instance, the 1990 Individuals with Disabilities Education Act (IDEA) combined the vocational rehabilitation and special education needs of students with disabilities [IDEA, 602(a)]. Usually local and state dollars are used to

pay for these transition services with a smaller portion coming from the federal government.

Further, vocational rehabilitation services have been available since the early 1900s. While the focus of rehabilitation legislation has changed, eligibility for individuals who experience physical or mental impairments that result in a substantial impediment to employment has also evolved. Generally, federal and state dollars are used to pay for those services. Local funding is usually not added to the state and federal mix. The purpose has always been to provide services that would enable employment situations to be optimized.

Given the evolution of special education and vocational rehabilitation programs, it is not likely that chronically ill children will be able to access these programs. Unless secondary issues are present, a condition of chronic illness, per se, does not satisfy program eligibility requirements. Students with chronic illness, then, will need to utilize the more traditional services provided in education systems for transition from school. As complicating factors such as type of illness will be present, additional knowledge, skills, and abilities will need to be used by educators and counselors.

Career Development

Career development is usually construed as a long-term endeavor in which an individual matches interests and abilities with opportunity and availability. Some development processes are planned and directed while others appear random and chaotic. Differences among processes are as varied as are the individuals who are involved. Additionally, interactions among families, school systems, community, and situational interfaces contribute to the myriad of variables that affect career choice. What can be said is that each illness presents a challenge that should be added to the already large group of factors that might influence or even dominate choice.

Much like Hanley-Maxwell, Szymanski, and Owens-Johnson (1998), a review of career factors reveal several areas of commonality and recommend themselves to the consideration of transition for an individual.

First, a chronic illness complicates an already complex transition process. Moving from school to work is fraught with difficulties in the best of situations. While agencies and systems might provide services for eligible individuals, chronic illness, per se, usually do not meet eligibility levels.

Second, extensive (not enmeshed) involvement with family facilitates development of career attitudes and attributions. Chronic illnesses may cause individuals to be protected from many career investigation and social development situations so that the nexus of home and career is truncated. Mediation can occur with a review of the home involvement.

Many times chronic illness limits exposure to situations that open up or provide for unexpected information about careers. Serendipity or shared peer experiences are often missing due to the protected nature of the person with chronic illness. Further, diagnosis, planning, and treatment of the disease or illness provides over exposure to a medical model view of the world and a limiting notion of career. It is difficult to learn from new experiences if the illness limited learning situations that might provide exposure to new interests are not available.

Fourth, attitudes about what can be expected from someone with chronic illness might preclude an ideation and exploration of certain careers. While a career exploration process should include a differential decision making process, models that exclude any number of career from any consideration may prove to be a disservice. The ability to participate in many mutual interest endeavors with peers often proves to decisive for adolescents. Many individuals with chronic illness view themselves as isolated and unable to participate in these processes.

Finally, the ongoing role of family and community should be examined to determine the need for ongoing support. As part of the individuation process involves the making and remaking of support structures, individuals with chronic illnesses may see themselves apart from these support roles. Premature breaks from these supports may be as detrimental as ties that linger too long and constrict maturation processes.

Probable Outcomes

Career transition has a clear break with high school gradation. As was noted earlier, higher education experience is valued by both employers and individual workers. A high school diploma is now such a given that most careers don't even mention the need for one; knowing that this academic foundation will be there. A review of the sociodemograhic history of differences between those who complete high school and those who don't is about a stark a contrast as exists in sociodemographic data.

While dropout rates for students with chronic illness should be near that of other students (12%-16%) it is likely larger. Due to extended treatments, students are often disadvantaged in academic competition due to absences, cognitive disruptions, and shifting life management issues.

Evolution of Transition

While transition exists as a seamless evolution from interests, capabilities, and serendipitous opportunities, several portions of the transition can be singled out for examination. These include individual and family decision making, school services, and postsecondary opportunities.

Individual and family decision making should examine current and exp.cted vocational and educational opportunities for the student. As

individual illnesses impact the direction of decision making, a beginning point should be the aspirations of the student, not the perceived limitations of the chronic illness.

However, recognition of limitations of chronic disease processes should not be ignored. For instance, if physical or cognitive limitations exist, the assessment of opportunities should include that type of assessment. Content of the assessments completed should include potentials that balance limitations. While inherent barriers may exist due to chronic illness, persistence of those barriers is an equally important assessment.

Even though important differences exist among students with chronic diseases and those without disease processes, assessments should be done within settings usually utilized in education settings. Some concern might be expressed about how students with chronic illnesses could express themselves in the context of post secondary education or vocational opportunities. Additionally, maintaining or enhancing social integration for individuals with chronic illness would be an important consideration. Finally; knowledge, skills, and abilities acquired in high school settings transfer well to postschool situations (Hasazi, Gordon, & Rose, 1985).

Students with chronic illnesses can often perceive themselves as isolated, different, and not worth attention by others. Targeting these students for feedback to help form future behavior and decision making involving social skills can ameliorate skill deficits (Chadsey-Rusch, 1986).While techniques of problem solving vary, an approach that includes problem identification, generation of alternatives, assessment of alternatives, and monitoring of selections should be included for generalization to additional situations. Students with chronic illnesses should include issues that deal with initiation, self-assertion, and self-correction. The context of these teaching procedures can be enhanced when used within the generalization of other teaching practices.

Currently a number of assessment systems and instruments can be used to assist students, families, and educators. These include, but are not limited to McGill Action Planning System (Forest & Lusthaus, 1987), Lifestyles Planning Process (O'Brien & Lyle, 1987), Personal Futures Planning (O'Brien, 1987), the family-centered approach to early intervention (Dunst, Trivette, & Deal, 1988).

Career specific assessment instruments and systems include AGS Careers Catalog (1997); Strong and MBTI Career Report Consulting Psychologists Press (1997); Parent Behavior Checklist (PBC), Parenting Stress Index (PSI), and Assessment of Interpersonal Relations (AIR) Clinical Psychology Publishing Company (1994); Adult Personality Inventory (API) Institute for Personality and Ability Testing (1997); Inventory for Counseling and Development (ICD), Self-Description Inventory (SDI), Temperament and Values Inventory (TVI), Campbell Interest and Skill Survey (CISS), Career Assessment Inventory (CAI), and Interest Determination, Exploration and Assessment System (IDEAS) NCS Assessments (1997); Career Decision Scale (CDS) and Self-Directed Search (SDS) Psychological Assessment Resources (1998); Transition Planning Inventory (TRI), Work Adjustment Inventory (WAI), Occupational Aptitude Survey and Interest Schedule (OAS & OIS) Pro-Ed (1996); Career Interest Inventory (CII) The Psychological Corporation (1996); Differential Aptitude Tests (DAT), Career Interest Inventory (CII), and Ohio Vocational Interest Survey (OVIS) The Psychological Corporation (1997); Adjustment Scales for Children and Adolescents (ADCA), Comprehensive Scales of Students Abilities (CSSA), Gardner Social (Maturity) Development Scale (GSDS), and Self-Esteem Index (SEI) Psychological and Educational Publications (1995); and Tennessee Self-Concept Scale (TSCS), California Life Goals Evaluation Schedules (CLGES), Forer Vocational Survey (FVS), Assessment of Career Decision Making (ACDM), and The Vocational Interest Inventory (VII) Western Psychological Services (1998). Further research needs to take place to determine the extent of standardization and validity applicability for individuals with chronic illness.

Transition to an area of best choice presupposes that assessment issues can be resolved. Recognition of career choice should be structured enough to provide direction for decision making, yet flexible enough to recognize that changes will need to take place.

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